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The Evolving Role of Leadership and Change in Maternal and Child Health Epidemiology

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Beginning in the 1980s, there was a growing recognition of the need to quantify the work and contributions of state maternal and child health (MCH) departments [1]. In 1987, the Maternal and Child Health Epidemiology Program (MCHEP) was initiated by the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) to provide epidemiologic leadership for State MCH programs [2, 3]. The success of the MCHEP spawned subsequent initiatives to build MCH data capacity including the development of a National Action Agenda, which was led by the Association of Maternal and Child Health Programs (AMCHP) and CityMatch, and included other national organizations such as the Association of Schools of Public Health, the Association of Teachers of Maternal and Child Health, the Council of State and Territorial Epidemiologists (CSTE), and the National Association of County and City Health Officials [4, 5]. The National Action Agenda focused on increased funding in CDC and HRSA for three areas: better training, stronger data and information systems, and more field-based capacity building. These efforts contributed to a plethora of programs in these areas, including the strengthening of masters, doctoral, and post-doctoral MCH epidemiology training opportunities through programs such as: the MCHB MCH Graduate Student Epidemiology Program for master's level students; the MCHB MCH Epidemiology Doctoral Fellowship Program; and the CDC/MCHB MCH Epidemiology Master's and Post-Doctoral Fellows Program, directed by CSTE [6, 7]. Programs to strengthen the analytic skills of the present workforce have included: the MCHB/CDC MCH Epidemiology Methods Training Course; the MCHB MCH Navigator,

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designed to address and support continuous MCH professional and workforce development needs, including epidemiology; the CDC/MCHB pre-conference trainings at the MCH Epidemiology Conference, administered by the Association of Maternal and Child Health Programs, which have featured such trainings as data linkage, geographic information systems, and needs assessment; pre-conference trainings and focused MCH epidemiology tracks at the CityMatCH and Association of Maternal and Child Health Program Conferences, including trainings on synthetic estimates, small area analysis, and communicating data findings; the CDC evaluation practicum developed to provide a framework for evaluating state MCH programs; and the CDC distance-based course in epidemiologic methods [8–13]. Additionally, the MCH Epidemiology Conference was established in the mid-1990's, and has served as the focal point for the latest developments in the field [14, 15].

In turn, many factors in maternal and child health data collection and analysis have improved. Since the inception of the program, the capacity of State MCH programs to provide and analyze data has greatly increased [16–19]. Data systems unavailable to states before the late 1980's, such as linked birth-infant death files, the Pregnancy Risk Assessment Monitoring System (PRAMS), the Youth Risk Behavioral Surveillance System, the Title V Information System, the National Survey of Children's Health (NSCH), the National Survey of Family Growth, and the National Survey of Children with Special Health Care Needs, are now routinely used. Data systems that are state-based have greatly enhanced our understanding of population-based factors, and have influenced state policies in maternal and child health. For example, data from the Pregnancy Risk Assessment Monitoring System has provided information on state smoking policies on maternal smoking and quit rates [20], breast feeding rates as affected by policy on hospital formula bags [21], and state early discharge policies for newborns [22]. Furthermore, advanced computer software has allowed data systems like vital statistics and Medicaid data to be linked to examine such issues as birth outcomes among Medicaid recipients.

A major challenge for leadership in maternal and child health epidemiology was how to increase data and analytic capacity at the State level. In that regard, there has been a great deal of success, as measured by CSTE's periodic surveys on epidemiologic capacity. From 2004 to 2009, MCH State epidemiologists had the second largest increase in staffing and analytic capacity among all the epidemiologic areas examined, after bioterrorism [23]. As a further measure of success, these assessments also indicated that the percent of states reporting full maternal and child health epidemiologic capacity increased during that time period from 43 to 55 %.

Maternal and child health outcomes have also changed since the inception of MCH epidemiology programs. The preterm birth rate and low birth weight rate both rose over 20 % between the early 1990's and 2006, then began a slight decline [24]. The cesarean section rate climbed almost 50 % between 1996 and 2010 [24]. The Back to Sleep Campaign and the introduction of pulmonary surfactants in the early 1990's led to a decline in the infant mortality rate through 2000. Infant mortality remained stagnant till 2007, when the decline resumed [25, 26]; yet despite recent declines, the US ranks 34th in the world for infant mortality rates in 2011 [27]. The percent of children with special health care needs has

increased, and much of that increase has occurred among developmental conditions such as autism spectrum disorders and attention deficit disorders [28]. The percent of children classified as overweight or obese increased dramatically between 1990 and 2010 [29, 30].

The analytic understanding of these changes in maternal and child health would not have occurred without the work of MCH epidemiologists.

But, times have changed, and therefore, the challenges for MCH epidemiology have changed too. The passage of the Affordable Care Act (ACA) in 2010 increased the emphasis of the health care system on prevention and health promotion, as well as increasing coverage for those previously uninsured. Budgetary limitations have meant cutbacks at the local, State, and Federal levels, as well as even greater demands for accountability for dollars and demonstration of impact. It is becoming more difficult and costly to obtain needed data. There has been a decline in the response rates for all types of surveys, whether they are in-person surveys, like the National Health Interview Survey, or telephone surveys such as the National Survey of Children's Health. It is no longer enough to report simple associations only between a risk factor and an outcome. Theories on life course and fetal origins of adult disease have accelerated the need to account for the complexities that shape the health of children. Prenatal and early life experiences have been seen as having increasing importance on the health of adult populations [31–33]. Advances in communication technology have also affected the speed and mechanisms of MCH information: policy makers and the public expect data and information to be provided more rapidly.

What are the challenges that leaders in MCH epidemiology will face in the future?

(1). Evolution in analytic approaches and methods

MCH epidemiologists will increasingly need to apply techniques developed in areas other than epidemiology. Fields of knowledge are becoming more integrated and MCH epidemiology will be no exception. MCH epidemiologists will need to draw upon skills originating in other areas. Multilevel analysis is a prime example. Beginning in sociology, it is now more common in MCH epidemiology. Return on investment (ROI) is another example. ROI originated in economics, yet in a time of austerity and accountability, ROI is going to be crucial for the sustainability of MCH programs. Quality improvement is a third example, being used more commonly in clinical practice, but now becoming more important to our field as there will be more focus on the quality of health services, with the implementation of the Affordable Care Act. It will be the job of leaders in MCH epidemiology to introduce new areas of knowledge in order to address new challenges.

The development of the life course theory and the fetal origins of disease theory will not only portend a shift in how MCH programs are developed, but in how they're measured. MCH epidemiologists will need to be versed in how to conduct longitudinal analyses. These changes, however, will provide opportunities in areas such as preconception health and care.

(2). Evolution in measurement

MCH epidemiologists will also be called on to measure new areas related to health care reform. How do we measure the varied effects of the ACA on children when States can choose different ways of implementing the act? How will we measure health insurance—will underinsurance become a primary issue, rather than no insurance? How will we measure disparities in health outcomes among those who are intermittently insured in health exchanges, those who are insured but still have unmet needs, and those who are insured but have limited access (e.g. geography) to care? How will MCH epidemiologists effectively measure non-clinical factors such as care coordination, particularly for children with chronic conditions [34]. With the potential of expanded health insurance coverage, safety net programs that provided clinical care (e.g. breast and cervical cancer screening) may need to evolve [35].

There will need to be increased focus on measuring the success of Title V programs, and that will necessitate a change in how we measure performance. MCH epidemiologists will be increasingly called upon to either demonstrate the effectiveness of Title V programs or be able to measure why they might not be working, and have the courage to communicate their findings, regardless of the results.

(3). Evolution in communications

How will MCH epidemiologists best utilize social media to communicate results to the public? As an example, Text4Baby, a free text messaging service, provides timely health information to pregnant women and new mothers to help them improve their health and the health of their babies, and has reached over 320,000 mothers [36]. Challenges for MCH epidemiologists will be to continue to reframe data for the new generation of social media, and develop methodologies to assess the impact of social media.

Moreover, training in how to communicate with policy makers or the public has not been traditionally provided, but with increased accountability, MCH epidemiologists will need to be able to communicate findings in an effective way, thereby being propelled into leadership roles.

(4). Evolution in timeliness for collecting and disseminating data

What will be the mechanisms for collecting and disseminating data more rapidly? There are emerging examples where data are being produced more rapidly. At the state level, vital statistics in Florida and Ohio are now available soon after their compilation. Vital records reporting on births in Ohio are available in real time and query-based birth data in Florida are available within a week. Data on death events are slower but can continue to improve with the incorporation of computerized death certificates and State Electronic Transfer of Vital Events [37]. National reporting has improved but is dependent on the timeliness of state/region/tribal vital records jurisdictions and is only as fast as the slowest reporters. In addition to improving timeliness, national data reporting systems are providing more customer-friendly query systems for rapid reporting. Examples include HRSA's National Data Resource Center for data on the National Surveys of Children's Health and the

National Surveys of Children with Special Health Care Needs [38]; March of Dimes' Peristats [39]; C-Ponder, a PRAMS query system [40]; Assisted Reproductive Technology (ART) Surveillance System on clinic-based success rates; and recently, preterm and multiple ART birth rates by state [41]; and CDC WONDER, an all-encompassing query-based system that includes natality data [42].

The need for even more rapid data is being addressed at the Federal and State levels, as well as by professional organizations such as the National Association of Public Health Statistics and Information Systems (NAPHSIS) [43]. National reporting is also starting to provide more emphasis on provisional data for vital statistics and other systems are following. The National Survey of Children's Health is being revised to collect annual data compared to every 4 years.

(5). Evolution in leadership

Larger forces, often outside the realms of either maternal and child health or epidemiology, are, nonetheless, shaping the future of MCH epidemiology. Budgetary constraints, increasing accountability, major changes in our health system, as well as technological and communication advances will all have major impacts. Future leadership in MCH epidemiology will involve new skills, not only the ability to do complex analyses, but the ability to imagine a more complex world, one in which it will be necessary to collaborate with experts in other areas including economists, insurers, housing specialists, environmental scientists, hospital administrators, informatics specialists, and health communicators.

In sum, from its origins over 25 years ago, the MCH epidemiology field has grown from a single program to an invaluable part of every State's MCH work. It has grown both from outside pressures, such as mandates for increased accountability, as well as the recognition within MCH that the efficacy of our efforts can only be evaluated with timely and properly analyzed data. Yet, leadership can be defined as both the ability to recognize the need to adapt to changing times, as well as the ability to frame the future. Leaders in MCH epidemiology will face an array of varied challenges in the future, including fiscal restraints, increased pressure for accountability, ever more complex interactions between health services and health outcomes, understanding and explaining the changing conditions of children, and the expectations for more rapid responses due to the capabilities of new technology and social media. As MCH epidemiologists, devoted to improving the health of infants and children, we can assume nothing less than each of us will be viewed as leaders or experts by program managers, policy makers, or the public.

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